

Zero-to-NEWS Three

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The Early Intervention Section of the State Department of Health provides developmental services for any eligible child from birth to three years of age in five areas: physical, cognitive, communication, social or emotional, and adaptive.

Services are available on all islands and there is no cost to families.

For more information, please contact our Hawaii Keiki Information Services System (HKISS) referral and information line at 973-9633 for Oahu and 1-800-235-5477 for Neighbor Islands.

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COMMUNICATING thru *Sign*

A growing trend in parenting is developing across the nation where hearing babies are learning to sign before speaking. According to studies conducted by Drs. Linda Acredolo and Susan Goodwyn of the University of California at Davis, signing aids speech and cognitive development. Babies are also less frustrated and have fewer tantrums, have a greater interest in books, and later improved skills in reading and math. A recent July article featured in the Honolulu Advertiser found that several local families have also adopted this trend and started signing with their babies.

Signing can also be useful for babies with special needs. Joshua Hircock, who was born with mosaic trisomy 8, is learning how to sign as part of his early intervention (EI) services. Mosaic trisomy 8 means there is an extra 8th chromosome but because not all the cells contain the extra chromosome, it is not clear how this will affect his development.

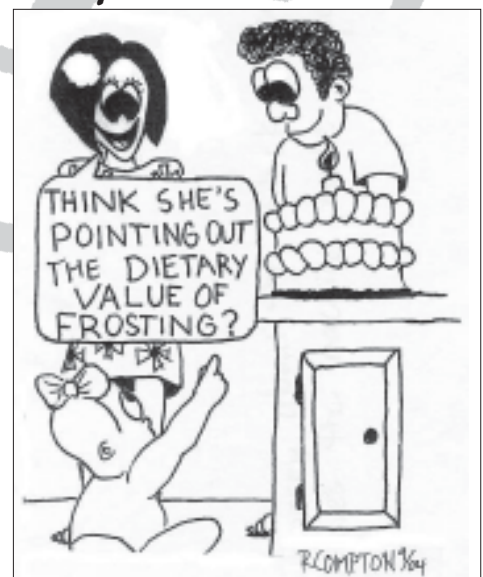
"Joshua was born with severe contractures, missing a part of his brain, his fingers wouldn't work, and his legs wouldn't move. The one good thing about mosaic trisomy 8 is we don't know what Joshua's potential is as some tissues are normal, some are not. We won't know until he grows up.

This gives us a lot of hope," states Mimi, Joshua's mother.

As Joshua progressed in his gross and fine motor skills, Mimi began to notice that he wasn't babbling. "He seemed to have a couple of words and then he lost them. He is bright but was frustrated because his only way of communicating was by pointing at me," commented Mimi. In her research to understand Joshua's condition, Mimi found a 35 case study on children with Trisomy 8. "The majority of kids with Trisomy 8 have a lot of disabilities. A mother collected data on 35 case studies and found 57% of the children were non-verbal or never speak."

(Continued on page 3.)

Randy's World by Randy Compton



CHAIR'S MESSAGE

by Jennifer Schember-Lang

I have a small book (3 inches square) that I carry with me and pull out from time to time when I need a little "charge."



Today I read, "There are many wonderful things that will never be done if you do not do them."

(Charles D. Gill)

You may soon have a wonderful

opportunity to build parent involvement and leadership in the early intervention system in Hawaii.

Are you a parent interested in:

- Gaining knowledge about effective leadership, organizational culture, the unique role that parents play on the HEICC, **and** acquiring leadership skills that will support parent leaders

- Helping develop strategies to assure a stronger and more diverse parent voice that will have an effective impact on policy development related to services for young children and their families

- Willing to work with others to look at parent needs, and plan and hold some kind of event or activity to address those needs.

Are you a professional working in the field of early intervention and interested in:

- Acknowledging the importance of parent-professional collaboration and helping build an effective team of parent leaders.

The National Parent Leadership Development Project for ICCs (early intervention coordinating councils) will hold their Leadership Institute tentatively scheduled for May 2005 in San Francisco. Hawaii would like to

send a team of up to six participant parents and one professional.

In the intensive four-day institute, Hawaii team participants would work with members from six other teams from across the country. The Institute agenda includes interactive activities and discussions centering on building intercultural communities, interpersonal communication skills, how to function as a leader in a conflict situation, and leaders as facilitators.

Each state team has an opportunity to begin the planning of a unique activity to be carried out in their home state within nine months of the Institute. And parents who participate on the Hawaii team will be part of a nationwide network of parent leaders mentoring and supporting each other with access to a website, a newsletter, and other resources.

(continued on page 4.)



JUST ASK!

Guest Contributor:
Adam Baron

Dear Adam: What is H-KISS and what is it about?

---A curious parent

When people in the community hear the name H-KISS, they don't always know what it means but many have heard of it. H-KISS stands for the Hawaii Keiki Information Service System. H-KISS is part of the Early Intervention Section in the Hawaii Department of Health. It serves as an information and referral service for families of children aged birth to three years with concerns for their child's health and development. We receive referrals from parents, pediatricians, hospitals, the military, public health nurses, preschools, and community health centers, just to name a few.

The easiest way to contact H-KISS is by telephone. When we receive phone calls, we take down the information necessary to determine where to refer a family within the Hawaii early intervention (EI) system, and process the paperwork necessary to link a family with services. Our most important job is to listen. Families are concerned for their child's health and sometimes express a variety of emotions during our conversation. We find that listening with compassion and asking the right questions expedites the process so that their children can get the services they need in a timely manner.

Once families are referred to an EI program, a care coordinator (CC) contacts them immediately. The CC acts as a family's primary point of contact and will walk them through the rest of the steps necessary to evaluate their child's physical, social-emotional, communicative, and thinking abilities and to decide with the family if developmental services might be necessary. All services offered are

geared to support families and are scheduled so services are convenient in both time and location. Services are provided at no cost to the child and family.

In addition to processing referrals, H-KISS also provides information about EI services and other related community options to callers. We provide information in the form of brochures, letters, telephone numbers, and web-addresses that are relevant to the caller's needs.

H-KISS is often the first point of contact that families have with the State's EI system. If you have concerns about your child's development or have questions about early intervention services please call us at 973-9633 between the hours of 8:30 am and 3:00 pm Monday through Friday. If you call after hours, please leave a message and we will return your call within twenty-four hours. We look forward to hearing from you!

(Adam Baron is the H-KISS Supervisor of the Early Intervention Section.)

Project SEEK by Taletha Derrington

From 1999-2001, the Early Intervention (EI) Section partnered with the University of Hawaii Center on Disability Studies to improve outreach to primary care physicians (PCPs). Beppie Shapiro and myself, Taletha Derrington, were the researchers who led this partnership. Why did we do this? An evaluation of EI "Child Find" in 1997 produced alarming results:

- Over 26% of children with significant special needs missed out on EI from 1991-1994.
- 81% of families interviewed had shared concerns about their child's development with their PCP, but no action was taken. 66% were told to "wait and see."
- 15% had a PCP who shared their concern, but made no referral.
- Many physicians lacked information or had negative attitudes about EI.

(Sign--continued from page 1.)

A speech therapist at Tripler told Mimi that sign language was a 'good way to help children who aren't talking.' Although sign language services at EI are usually provided for children who are deaf, Mimi asked for services based on the possibility that Joshua may be 'functionally mute'. As a result, EI's hearing specialist now visits the Hircok family every two weeks to teach Mimi and Joshua how to sign.

"The signing helps a lot—at least now Joshua can explain what he wants. When he wants to go out and play with the dogs, he'll come and do a 'please' and 'dog' (Mimi illustrates with her hands). He can tell me if he wants milk or water. When we go for a walk, he'll point out the birds and cars by signing. He is more social. He tells me what he is thinking and shows me his intelligence. It is very easy to assume if a child can't talk that they are not bright. The other day he had a flashlight that wasn't working and I signed that 'it's broken.' He signed

Something needed to be done! So a project called Strategies for Effective and Efficient Keiki Find (Project SEEK) was initiated to increase referrals and improve communications between PCPs and EI.

Project SEEK had two strategies. Our first strategy was informative and persuasive presentations to PCPs; the second was enhanced communications between programs and PCPs. Communication forms with information about EI were created for each step from referral to discharge. For example, the "notice of referral status" form indicated whether the program had contacted the family, and whether the family agreed to an evaluation. The form also listed EI eligibility guidelines.

We implemented these strategies with Maui EI and public health nursing programs in 1999-2000, and West and North Hawaii programs in 2001. We are deeply grateful for their collaboration!

Our efforts paid off! Our evaluation showed physician referrals increased in both communities. Compared to average year-to-year variation in PCP

back 'yes' and agreed that it was broken and then signed 'please change,'" describes Mimi. Signing has greatly supported Joshua's development.

Although Joshua is learning to sign, he is also receiving speech therapy under EI. "Yesterday, when he was signing 'ball', he made the lip movement for 'ball' but no sound. The other reason we decided to sign was because it stimulates that part of the brain that deals with expressive speech. The signing helps connect the receptive track to the expressive. The speech therapist is incorporating the signs with speech therapy. Last time we spoke, she said she had some mouth exercises because I want him to speak," continues Mimi.

Ultimately, Mimi is hoping to 'mainstream' Joshua. Says Mimi, "I believe he can do it—he knows what is going on—it's just a matter of giving him the tools. I am hoping to put him in a situation where he is not judged by what he has but if it's obvious that it is not a level he will obtain then I just want the best for him."

referrals, physician referrals went up over 6 times on Maui and over 5 times on the Big Island. Communications between EI programs and physicians was impressive. EI staff reported that PCPs began to respond to invitations to provide input to IFSP meetings; two years later, programs still report good communication – "PCPs now call the Kona Early Childhood Services Program and talk-story. This is a BIG STEP because it wasn't happening before!" PCPs' evaluations of the outreach were positive overall, and they enjoyed meeting EI staff. One PCP, who didn't use the program before, now does. Despite the increased workload, EI staff know it was a valuable effort.

I am now presenting Project SEEK's results and materials to EI programs around the state. Next year we hope to offer training on presenting EI to PCPs. All Project SEEK materials are available for download at www.seek.hawaii.edu. Check it out, use it, and let us know how you like it!

LEARN ABOUT EI

The Early Intervention Section is providing a 3-day "Early Intervention Orientation" that covers the following topics.

Day 1: History, Law, Eligibility, Early Intervention Services and Programs, Referral Process, Family-Centered Care, Cultural Sensitivity, Communication, Procedural Safeguards, and an update on Felix Consent Decree issues.

Day 2: Care Coordination, Home-based Skills, Safety/Boundary Issues, Individualized Family Support (IFSP) Process, and Natural Environments.

Day 3: Teaming, Transdisciplinary Approach, and Transition.

The trainings are open to early intervention service providers, family members, and physicians statewide. If you are interested in attending or would like more information, please call Stacy Kong at 973-1112 or email stacy.kong@fhsd.health.state.hi.us.

(Chair's Message--continued from page 2.)

Expenses for Hawaii team members (airfare, hotel, meals, and materials) will be covered and supported by both the National Parent Leadership Development Project for ICCs (a project of the Federation for Children with Special Needs) and the Hawaii Early Intervention Section. A meeting is currently being planned to share more detailed information about the Institute including the recruitment or application process for interested parents and professionals. If interested in attending this meeting, please contact Karen Ho at 808-973-9659 and you will be contacted when it is scheduled.

You may want to check the National Parent Leadership website at www.iccparent.org for more information. And remember, you can be part of the expanding family support efforts in Hawaii for young children and their families because you took hold of this opportunity.

NOTEWORTHY

Coming up! Early intervention services will be expanding in the Waipahu, Mililani and Windward (Kaneohe, Kailua, and Waimanalo) areas of Oahu. Be on a lookout for more information in future newsletter issues.

Adjust your favorites list in your web browser. Our website address was shortened to <http://www.hawaii.gov/health/family-child-health/eis>. If you can't remember our web address, visit www.google.com and enter 'early intervention Hawaii' and we should be the first link to boot up.

Make plans now! Visit us at the **New Baby and Kids Expo** at the Blaisdell Center on November 20-21, 2004. A fun outing before the holiday season begins.

Interested in visiting your legislators and telling them about your

experiences with early intervention services? Come join us on **Champions for Children Day** at the State Capitol on January 12, 2005. For more information, please contact Karen Ho at 808-973-9659 or by email at karen.ho@fhds.health.state.hi.us.

Mark it on your 2005 calendar! Visit us at the **Keiki Resources Fair 2005** on January 22-23, 2005. Lots of information on keiki programs, services and products. Will be a blast!



Linda Lingle, Governor
Chiyoine Leinaala Fukino, M.D.,
Director of Health

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